BEFORE THE INDIANA STATE DEPARTMENT OF HEALTH

AN ADMINISTRATIVE RULES HEARING LSA DOCUMENT #09-1

HEARING OFFICER REPORT

This matter came before the duly appointed Hearing Officer, Morgan E. McGill, on the 30th day of June, 2009, at 10:00 a.m., at the Indiana State Department of Health (ISDH), 2 North Meridian Street, Indianapolis, Indiana, Rice Conference Room.

Notice of time and place of the hearing was given as provided by law by publishing on June 5, 2009, in the *Indianapolis Star* and by publishing in the *Indiana Register* dated June 3, 2009. Proof of publication of this notice has been received by the ISDH and the notice and proof are hereby incorporated into the record of this cause by reference and placed in the official files of the ISDH.

There were no oral statements.

WRITTEN STATEMENTS

No written comments were received at the time of the hearing. The record was left open until July 8, 2009, close of business.

Written comments from persons who did not testify at the Public Hearing are summarized as follows:

- 1. Valerie Wood, public, noted that the new cap on Applied Behavioral Analysis (ABA) therapy proposed by the rule may affect the children who have been progressing using that treatment, as should the family reach the maximum covered dollar amount and not be able to continue due to the expense, there could be a regression by the child. Mrs. Wood was also concerned that the public may not be aware of the public hearing, as she found that it was very difficult to have discovered the announcement of the Notice of Public Hearing. Mrs. Wood's comments are attached and incorporated by reference as **Exhibit 1**.
- 2. Gary Ricks, Staff Attorney, Indiana Protection and Advocacy Services (IPAS), commented that his organization has been contacted by a family unhappy with the proposed

change to travel reimbursement due to take effect by passage of final rule. He stated that the individual stated that the rate of reimbursement which came into effect by emergency rule as of July 1, 2009, will not cover the costs associated with travel to be transported to medical appointments. As the individual cannot manage these costs out of pocket, access to necessary medical appointments is "seriously curtailed." Mr. Ricks' comments are attached and incorporated by reference as **Exhibit 2**.

- 3. Valera Potchka, program participant, noted that her son uses the program for supplemental coverage for autism therapy as her self-funded insurance will not cover recommended therapies for autism. She commented that ABA therapy is much needed and highly effective. She stated that the program participants had not been notified of the decrease in "income guideline" for families and that she learned of the cap on ABA therapy through the Indiana State Department of Health's website. She commented that autism families are already short on funds due to many doctor visits and other costs associated with autism. She also stated that children with autism do not deal well with change and that they will face a major change if they will now have less therapy. Mrs. Potchka's comments are attached and incorporated by reference as Exhibit 3.
- 4. Claudia Burrows, program participant, commented that she thinks a cut to ABA therapy is a reasonable budgetary cut. She noted that she is the parent of three (3) children, on the autism spectrum. She commented that the travel cut, in particular, has her concerned given the drastically increasing price of gasoline and vehicles. She commented that the change may force many two-income families to choose to have one person stay home and not work in order to ensure that their children receive the necessary benefits. She commented that this will likely result in an increased burden on other social programs, including Medicaid (which has a higher reimbursement rate for travel than the Children's program). She notes that the program should continue to encourage parents to stay in the workforce, where possible. Mrs. Burrows' comments are attached and incorporated by reference as **Exhibit 4.**
- 5. Holly Petre, program participant, commented that she doesn't understand why reimbursement for travel was cut. She notes that her child is three (3) years old and has had ten (10) surgeries, can only eat pureed food, drink thickened liquids and cannot walk. She comments that it costs a lot to go back and forth to Riley Hospital in Indianapolis, from Angola;

310 miles round trip. She comments that when you must make appointments with eight (8) to ten (10) different doctors, you often cannot make the appointments on the same day, and food and hotel cots are expensive. Mrs. Petre's comments are attached and incorporated by reference as **Exhibit 5.**

6. Anonymous survey responder, Riley Hospital. This survey was forwarded by Riley Hospital Staff. The responder commented that the travel change was very upsetting, as the family may not be able to come down to Riley Hospital (Indianapolis) as often as they need to. The responder noted that the program should have either made the change where all travel was reimbursed and paid at a reduced rate of 22 cents per mile, or eliminated payment for the first forty nine miles of travel, but one or the other. This individual's comments are attached and incorporated by reference as **Exhibit 6**.

7. Janet Brecka, program participant, survey responder at Riley Hospital. This survey was forwarded by Riley Hospital staff. The responder commented that the family is very upset about the changes to the travel reimbursement. They have to visit two or four times per month because their granddaughter is on vent support. She commented that cases should be evaluated on a case by case basis. She commented that a child on life support should receive a full benefit while a child who comes only for one visit and has no major issue should qualify for a lesser benefit. She noted that her daughter was a single mother who recently lost her job and had very limited financial support. Mrs. Brecka's comments are attached and incorporated by reference as **Exhibit 7.**

All of the Exhibits referenced above are attached and incorporated into this report. Respectfully submitted to the Executive Board of the Indiana State Department of Health this 30^{th} day of June, 2009.

Morgan E. McGill
Hearing Officer

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	TO DESCRIPTION OF THE PROPERTY

McGill, Morgan E.

From:

V. Wood [VALWood@ameritech.net]

Sent:

Tuesday, July 07, 2009 12:05 PM

To:

McGill, Morgan E.

Subject: re ISA Document #09-1

Dear Ms McGill,

I appreciate the opportunity to participate in the hearing June 30th on this matter. Autism is a thorny issue for all concerned. The solutions proposed by this document could well be the best way to serve large numbers of families while taking an the state's budget needs into account. I would like to point out that, should a family elect to stop therapy because the covered dollar amount has been reached, there could be regression by the child, which would need to be regained later.

Another concern that I have, only marginally related to the issue at hand, is the surprise expressed to me at the appearance of a member of the public to a hearing. I found my way there after reading the public notices in the Indianapolis Star (print version). Is this the only way they are announced? Public notices make such difficult reading that they are in practice scarcely public at all.

Thank you for the opportunity to observe our government at work,

Sincerely,

Valerie Wood

MITCHELL E DANIELS, JR. GOVERNOR

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4701 N KEYSTONE AVE # 222 INDIANAPOLIS IN 46205 VOICE 317.722.5555 FAX 317.722.5564 TOLL FREE VOICE 800.622.4845 TOLL FREE TTY 800.838.1131 WWW.IN.GOV/IPAS

July 22, 2009

Indiana Department of Health Children's Special Health Care Services Section 7B 2 North Meridian Street Indianapolis, Indiana 46204

Dear Sir or Madam:

I'm one of the staff attorneys for Indiana Protection and Advocacy Program (IPAS). If you're not familiar with IPAS, we are a federally-funded state agency that advocates for the legal, civil, and human rights of individuals with disabilities.

I recently had an individual contact me about the issue of the reductions in travel reimbursement recently implemented by CSHCS. This individual reports that at the current rate of reimbursement, it will not cover the costs for him to be transported to necessary medical appointments. They do not have the money to pay the costs out of pocket, so their access to necessary medical appointments is seriously curtailed.

If possible, I'd like to get some information from your office about this change; 1) how many individuals will be affected by this change, and, 2) can you give me some information about this change came into effect, e.g., was this change formally promulgated as a rule? I'd appreciate any specific information you can give me regarding this issues.

If you need further information about this request, I'd be happy to discuss this further with anyone involved in the CSHCS program or your legal counsel. I can be reached at: (317) 722-5555, ext. 228, or via email at: gricks@ipas.in.gov. Thanks for your assistance.

Staff Attorney



Mitchell E. Daniels, Jr. Governor

Judith A. Monroe, M.D. State Health Commissioner



July 28, 2009

Mr. Gary Ricks Staff Attorney IPAS 4701 N. Keystone, Ave # 222 Indianapolis, IN 46205

Dear Mr. Ricks:

I have received and reviewed your letter regarding the change in family member travel coverage, recently implemented by the Children's Special Health Care Services Program in the Indiana State Department of Health. You indicated that you were a staff attorney for IPAS, a federally-funded state agency advocating for legal, civil and human rights of individuals with disabilities. You stated that you recently were contacted by an individual regarding the reduction in CSHCS travel reimbursement, who stated that, as a result of this change, costs for transportation to necessary medical appointments would not be covered. You requested details about that change.

Indiana's Children's Special Health Care Services (CSHCS) is a supplemental program that helps families of children with serious chronic medical conditions pay for treatment related to their child's condition. Children's Special Healthcare Services (CSHCS) is supported by Title V and State funds. The statutory authority for the CSHCS Program can be found in Indiana Code (IC) 16-35-2 and Indiana Administrative Code (IAC) 410 3.2.

This year, the program has faced reductions in available funding and has had to curb spending expenditures for its services which resulted in proposed amendments to the rule aimed at cutting increasing costs in non-core areas of the program. Although CSHCS will continue to pay for travel reimbursement to the parent or guardian of the under-age participant or to the participant of age for trips to approved health care providers, the first forty-nine miles per trip are never paid. Once a family travels 50 miles, the payment rate will be at 50% of the state travel reimbursement rate. The actual rate decreased from \$.44 per mile to \$.22 per mile.

The ISDH has an emergency rule in place which authorizes this change. The rule promulgation process is underway, and the public hearing for the rule change (LSA #09-1) was held on June 30, 2009. The Final Rule will go before the Executive Board on September 9, 2009, and your comments will be added to the comments received for consideration.

I hope this letter addresses your concerns. Thank you.

Sincerely,

Kathy Bowen, Director CSHCS Program



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McGill, Morgan E.

From: Bowen, Kathy (Kate)

Sent: Thursday, July 02, 2009 4:25 PM

To: McGill, Morgan E.
Cc: Bowen, Kathy (Kate)

Subject: comments on rule change

The only 2 comments on the rule changes are the two reprinted below: Valera Potchka concerning autism and Claudia Burrows concerning transportation. I also talked to a "Deana" from Homefront Learning today who may be sending me comments - I told her the deadline for submission. That is all I have received so far.

Thanks.

----Original Message----

From: Valerie Potchka [mailto:vpotchka2@verizon.net]

Sent: Thursday, May 28, 2009 9:41 PM

To: House District83

Subject: Email Your Legislator

Name: Valerie Potchka

Email: vpotchka2@verizon.net

Phone: 2604362969

Address: 5311 Crandon Lane

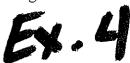
City: Fort Wayne

State: IN Zip: 46804

Comment :

I am contacting you regarding the recent changes to the Children's Special Health Care Services program. My son is a recipient of thisprogram and has been since 2007. Jack is four years old and hasautism. We turned to this program for supplemental coverage forautism therapy. Although Indiana has an insurance mandate for autismtherapies, our self-funded insurance does not have to pay for thetherapy and will not. The CSHCS program has allowed us theopportunity to receive the much needed and highly effective ABAtherapy that is recommened for autism. Yesterday I learned of thedecrease in income guideline for families. We have not been notifiedregarding this matter and the website does not reflect this changeeither, I found out through a disability group e-mail alert. This isvery unfortunate. Autism families are already short on funds due tomany doctor visits and other costs associated with autism. To makematters worse, I visited the website today to see if the July 1stchanges have been posted, they have not. I did however, find aposting regarding a cap that has been placed on ABA therapy. Again, we have not been notified. Children with autism do not deal well withchange. In one month, many of the children with autism will have

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amajor change in their routine, less therapy. I am very unhappy withthe decision to cut funding to this program.

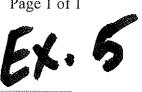
Dear Ms. Bowen,

Thank you for your response. I am happy to hear that you are delaying the decision to decrease eligibility and I hope that you can find other areas to cut the CSHCS budget. I think a reasonable cut is limiting ABA coverage (and I am a parent of three children "on the spectrum"). I am, however, extremely concerned about the reduction of payments for family travel, given the drastically increasing price of gasoline and vehicles. Unfortunately, the state may end up "robbing Peter to pay Paul" in this matter... two-income families currently utilizing CSHCS may be forced off the program, necessitating one parent leaving the workforce in order to assure that their child continues to have necessary benefits. This will diminish the state's tax base and increase the burden on other social programs including Medicaid (which will expend many times the CSHCS amount for transportation alone!). Perhaps it would do the state well to encourage parents of children with special health care needs to remain in the workforce, wherever possible. Programs such as CSHCS encourage people to stay off social programs such as Medicaid and to work harder to help themselves by reducing some of the extraordinary burdens they face as parents of special kids. I hope that budget decisions can be made with this in mind.

Respectfully, Claudia Burrows 805 W Dunn Ave Muncie, IN 47303

Sent to Representative Matt Bell

Kathy J. Bowen, Director CSHCS Indiana State Department of Health 2 N. Meridian St. 7B-01 Indianapolis, Indiana 46204 317-234-3113 kbowen@isdh.in.gov



McGill, Morgan E.

From:

Bowen, Kathy (Kate)

Sent:

Wednesday, August 05, 2009 12:04 PM

To:

McGill, Morgan E.

Subject:

FW: IQ Reply for Holly Petre

Attachments: Holly Petre.mht; Travelpetregov.doc

This came in today as a complaint about the travel change.

Kathy J. Bowen, Director **CSHCS** Indiana State Department of Health 2 N. Meridian St. 7B-01 Indianapolis, Indiana 46204 317-234-3113 kbowen@isdh.in.gov

From: Bowen, Kathy (Kate)

Sent: Wednesday, August 05, 2009 12:03 PM

To: Vrazel, JoEllen; Barlow, Teresa Cc: Bowen, Kathy (Kate); Rief, Kimberly Subject: FW: IO Reply for Holly Petre

Joey - This is a draft response to the email sent from Kim. Kim requests it be written for your signature and that you forward the approved email response by 8/12/09 (next Wednesday). Let me know if I need to make any changes. Thanks.

Kathy J. Bowen, Director **CSHCS** Indiana State Department of Health 2 N. Meridian St. 7B-01 Indianapolis, Indiana 46204 317-234-3113 kbowen@isdh.in.gov

From: Rief, Kimberly

Sent: Wednesday, August 05, 2009 11:03 AM

To: Bowen, Kathy (Kate) Cc: Barlow, Teresa

Subject: IO Reply for Holly Petre

I'm helping Scott Zarazee with IQ reply letters. Please compose/or have a reply letter composed for Holly Petre. The letter will be for your Assistant Commissioners signature. You should E-mail your response to Dr. Vrazel for her approval and you should forward the approved E-mail response to me by the close of business Wednesday, August 12, 2009. The letter should start out with something like "Thank you for contacting Governor Mitch Daniels regarding Children's Special Health Care Services. Governor Daniels appreciates the time you took to share your comments about such an important matter. As the Assistant Commissioner for Human Health Services at the Indiana State Department of Health (ISDH), he asked that I respond on his behalf."

HTML

E-Mail Viewer

Message Details Attachments Headers Source

From: "Web Form Poster" <eyotagaho@yahoo.com>

Date: 7/31/2009 6:57:27 AM

To: "webform@gov.IN.gov" <webform@gov.IN.gov>

Cc

Subject: Contact Form: other

I don't understand why you cut funding on the Children's SpecialHealth Care Services Program, as 7/01/2009.My letter sent from CSHCSstates this is a result of the current state of economy.I watch thenews daily and see government money going parks,police shooting range,your trip across seas, ect.More of a luxury than a need. My childneeds medical follow ups twice a month sometimes more. My daughter is3,has had 10 surgeries, can only eat puree foods, drink thinkenedliquids, and cannot walk. Why does the government take from thespecial need children?Our children with special needs deserve thefunding back that you the government took away. Why do the childrenhave to suffer? It cost alot to go to riley from angola, IN 310 milesround trip. When you see 8 to 10 differnt doctors you can't getappointments on the same day,and hotels and food aren't cheap. Thecity is costly. Please give us back our funding for the children'stravel reimbursement. CSHCS needs your help with this funding. PLEASEGIVE BACK FUNDING FOR THE CHILDREN. thank you. may the lord bless you.

Close

	: :

Thank you for contacting Governor Mitch Daniels regarding Children's Special Health Care Services (CSHCS). Governor Daniels appreciates the time you took to share your comments about such an important matter. As the Assistant Commissioner for Human Health Services at the Indiana State Department of Health (ISDH), he asked that I respond on his behalf.

Your email expressed concern with the cutback in travel benefits for CSHCS participants, and you questioned why this funding was decreased. You pointed out that your child has severe and ongoing medical needs, and that it is expensive to make the necessary trips to the doctor or other health care provider. You requested this decision be reconsidered.

Please understand that the program has faced reductions in available funding this year and was required to curb expenditures for its services. The changes made to the program are in line with the governor's request for savings, and were aimed at reducing costs in non-core areas of the program. The CSHCS Program attempted to make changes that took into account the best available estimates of the need versus potential funding. Although CSHCS will continue to pay for travel reimbursement to the parent or guardian of the under-age participant or to the participant of age for trips to approved health care providers, the first forty-nine miles per trip are never paid. Once you travel 50 miles, the payment rate will be at 50% of the state travel reimbursement rate. The actual rate decreased from \$.44 per mile to \$.22 per mile.

Indiana's Children's Special Health Care Services (CSHCS) is a supplemental program that helps families of children with serious chronic medical conditions pay for treatment related to their child's condition. As a supplemental program, CSHCS' consideration of payment would be secondary to other insurance or Medicaid. Your email did not state whether or not your daughter is on Medicaid; however, if she is, you may wish to contact them to see if they have any travel or transportation benefits that would assist you.

While I understand your concerns, it is regrettable that CSHCS is not in the position to rescind the reduction of travel benefits at this time.

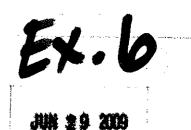
Sincerely,

JoEllen (Joey) Vrazel, PhD, MA Assistant Commissioner Health and Human Services Commission

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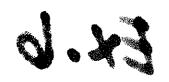
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CSHCS FAMILY SURVEY

Please circle your responses.
Please add any comments you feel may help us serve you better.

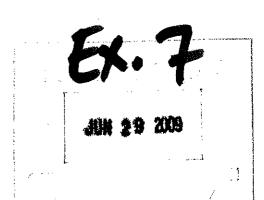
1	. Where did you complete your most recent CSHCS application?
	Riley Office Other Office
2.	How would you rate your experience applying for the CSHCS program?
	Very Satisfied Satisfied Unsatisfied Very unsatisfied
3.	Comments: I am very upset with the change with reimbursment and a single mother from by chicago area, and will start getting reimbursed \$50 round trip! It cos me way more then that to trave! Were you notified of a decision from the CSHCS program in the time you thought you should be?
	Yes No
	Comments: It took awhile before we got an answer.
4.	Has having your child enrolled in the CSHCS program made a difference in the life of your child?
	Yes No
	Comments: It has helped 30 much but now with this change its



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" feel that I can not bring my daughter to the hospital as much as she needs, and she's on life support.

I know the economy isn't doing good, expecially with slot of people getting I aid off (including myself) ind you guys are even hurting us worse! How can you seemake such dramastic change?! You should have done either one or the other with the \$22 or first 49 miks does ht count!! I am Very upset. I do not take advantage of anything I have alot going on, and now this is going to hurt me and iny daughter! I hope you can reevualate the situate situation, and maybe realize the true familys that need and rely on it to take there Kids to the hospital!



CSHCS FAMILY SURVEY

Please circle your responses.
Please add any comments you feel may help us serve you better.

1. Where o	lid you complete your most recent CSHCS application?
	Riley Office Other Office
2. How wo	uld you rate your experience applying for the CSHCS program?
Very Sai	disfied Satisfied Unsatisfied Very unsatisfied
(Comments: New Change are un Settling
3. Were you thought y	notified of a decision from the CSHCS program in the time you you should be?
	Yes (No)
	Comments: We direct the Receive Notice of Financial Charge Until we come for our visit on 1/29
4. Has havir the life of	g your child enrolled in the CSHCS program made a difference in your child?
	(Yes No
	Comments: See Back

We we have upset about the new Champs to the hand Remisurement Program. My Grand dauge ten is on Vent Support and Requires 2-4 visits per month. My daughter Recently lost her Job. Inis is going to be a hung challenge Financially for her to bring her down for I reat ments they Rely on this program to pay for trans portation Will Job Losses And Gas prices on the ries, how is a Single mom with limited family a limited Financial Support Suppose to get their child here For Treatment.

Each Case Should Bo evaluated on a Case by Case. A child on life Support Should get full Benefet When a child with only coming for visit and has no Major issue Should qualify for a lesson Benift,

Pleas Reconsider this decision.

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Janet. Brcka O Renolitia

Todd, Here are the 2

Megating Survey we received at the Riley

Agrice yesterday They have nothing to do

with Riley lent are to do with the new Have I know we can't change is, lub I felt like I should forward them on to year anyway,

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